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Portland, Oregon 97239

Ms. Vikki Wachino
Deputy Administrator and Director
Center for Medicaid and CHIP Services
U.S. Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244

Re: Public Comment on Oregon's 115(a) Medicaid Demonstration Waiver Renewal Application

Dear Ms. Wachino,

We are Oregon residents and the parents of a child with autism. For nearly four years we have been working to provide all children with the same access to care that has been of tremendous benefit to our son.

The Oregon Health Plan waiver must be revised before approval to remove any language that waives the EPSDT standard in order to ensure full EPSDT compliance.

We are encouraged by the early signs of success from the Coordinated Care Organizations, and look forward to the next steps in Oregon's healthcare transformation. However, it has become clear in recent months that at least some CCOs intend to save money by refusing to treat mental health conditions such as autism in children, even when those treatments are "above the line" on the Prioritized List, and that the Oregon Health Authority cannot or will not require them to provide that coverage. In asking for a waiver of the EPSDT standard, Oregon is asking the federal government to sanction that conduct. For that reason, we ask CMS to grant the waiver after amending it to explicitly hold Oregon to the EPSDT standard.

The denial of behavioral healthcare to children under the Oregon Health Plan violates two very important federal policies. The first is Early Periodic Screening, Diagnostic and Treatment (EPSDT), which makes healthcare for children a national priority by requiring Medicaid programs to cover all medically necessary diagnostic and treatment services for children regardless of whether such services

are otherwise covered under the state Medicaid plan for adults. The second is the Mental Health Parity and Addiction Equity Act (MPHAEA) as it covers Medicaid plans, which requires Medicaid plans to cover mental healthcare in parity with medical healthcare. These federal policies tell states trying to stretch their Medicaid dollars that they cannot cut costs by cutting care to children or by cutting care for mental health conditions. In other words, mental healthcare for children is not a discretionary expense that can be dropped in a lean fiscal year—it is to be prioritized, no matter how tight the budget. Sanctioning Oregon's CCOs' refusal to provide mental healthcare to children in order to save money would eviscerate these federal policies in Oregon and would make it very difficult to hold any state to those important federal standards.

Children of all races and backgrounds have autism or other mental or behavioral health conditions. But the refusal to cover mental and behavioral healthcare for children hits children of color hardest. Federal and state departments of education have found children of color are more likely to be punished in school for their unmet behavioral healthcare needs. In 2014 the Oregon Department of Education found that black special education students in Portland Public Schools were more than four times more likely to be suspended or expelled than other students, and were five times more likely to be suspended or expelled than white special education students. Children of color are also more likely to depend on the Medicaid system for healthcare. Oregon's refusal to require CCOs to cover behavioral healthcare for children means that a black child with autism is more likely to start school without having had early therapeutic intervention, is more likely to struggle in school, and is more likely to be punished for those struggles.

Additionally, foster children in Oregon rely on the Oregon Health Plan for care. Foster children in Oregon are nearly twice as likely to have an autism diagnosis as children who are not in foster care. Adequate behavioral healthcare can make the difference between a family that is able to cope with a child's autism and a family that feels forced to give up custody of that child. Once in state care, behavioral healthcare can provide an autistic child with his or her only hope of succeeding as a member of a foster family. When CCOs refuse ABA coverage to Medicaid families, they may destroy some families, and when they refuse to provide care to foster children, they deny those children homes.

The Prioritized List is a cost savings tool, nothing more. It is maintained by the Health Evidence Review Commission, which contains no adequate consumer representation and which limits the evidence it considers in order to limit access to care and save money. There is absolutely no justification beyond cost savings to use the Prioritized List to ration care for any Medicaid recipient, let alone a child who needs mental and behavioral healthcare which CMS has required other states to cover.

We have brought these concerns to the attention of the Oregon Health Authority, and we have been informed that OHA has no enforcement power over the CCOs. In other words, OHA cannot require a CCO to cover medically necessary care or even care that is "above the line" on the Prioritized List. CCOs often refuse to provide written denials of coverage, refuse to provide information about appeal rights to individuals who have been denied services, and refuse to provide information in the language spoken by the family. OHA is powerless to require them to meet state or federal law.

Oregon's CCO experiment was never meant to prove that Oregon could save money by refusing to care for its most vulnerable. The families of autistic children stand to benefit tremendously from the integration of mental and medical healthcare and coordination of care that the CCOs promise, but only if those CCOs are not permitted to save money by refusing to care for those children. I ask CMS to grant Oregon's waiver only after amending the waiver to explicitly hold Oregon to the EPSDT standard, and require Oregon to provide OHA with a mechanism to enforce EPSDT, mental health parity rules, and other CMS rules governing MCOs.

Sincerely,

Brenna Legaard

Scott Fournier